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Representative Steve Fontana Senator Joseph J. Crisco Joint Committee on Insurance and Real Estate Room 2800, Legislative Office Building Hartford, CT 06106 Phone: 860-240-0510

February 8, 2010

Dear Chairmen Crisco and Fontana and the Members of the Joint Committee on Insurance and Real Estate:

We are writing on behalf of Gina Gallivan in support of House Bill 5009, An Act Concerning Wellness Programs and Expansion of Health Insurance Coverage. It is an honor to support the efforts of Gina and her husband John Gallivan to pass such a bill.

Gina is truly a remarkable person. She has dedicated her life to education, teaching high school English and coaching tennis. She and her husband John, also a teacher, had just been married when she was diagnosed with Acute Lymphoblastic Leukemia (ALL) in April 2005. It is hard to imagine the fear associated with such a diagnosis, the intensive chemotherapy involved, and the life altering nature of the disease. Nonetheless, after spending a month in the hospital, Gina traveled from Connecticut to the Dana Farber Cancer Institute in Boston, Massachusetts on a routine basis and showed an extraordinary degree of courage. Unfortunately, the type of ALL she was diagnosed with predicted a high risk of relapse without an allogeneic bone marrow transplant, the type of transplant that requires another donor.

In an ideal situation, the recipient of an allogeneic bone marrow transplant will have a sibling with an identical bone marrow type. However, there is only a 25% chance that any sibling will match each other, and even with 4 siblings this is not a guarantee. If a sibling match is not found, which is more often the case, the National Marrow Donor Program (NMDP) is utilized, and a search is made for an "unrelated" donor match.

In order to become a potential donor and enter the NMDP registry, blood is drawn and the cells are examined for their specific HLA types. Matching between a donor and a recipient ideally occurs at 6/6 sites (full match). Anything less than this is associated with a higher mortality as a result of the transplant. Having more donors increases the probability of finding a full match and increases the likelihood that a particular patient such as Gina will be able to undergo a potentially lifesaving procedure.



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There are a number of barriers that limit participation in the NMDP registry. One key barrier is a fear of pain. It is important to emphasize that the risk to a donor is minimal, and that most transplants are now being performed using peripheral blood stem cells. In this setting, "bone marrow" is obtained from the blood, using growth factors to harvest stem cells from the blood, obviating the need for a potentially painful bone marrow biopsy. Other barriers that have been demonstrated in studies include cost and inconvenience. In fact, one study showed that up to 75% of donors in the registry come from community drives. Providing insurance coverage for the cost of testing for bone marrow donation is a significant advance in helping to overcome such barriers.

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Fortunately, Gina was able to find a 6/6 matched unrelated donor and underwent a bone marrow transplant using peripheral blood stem cells in September 2005. After a period of recovery she is currently doing well, free of leukemia, and back at work. She and John recently enjoyed the honeymoon they missed as a result of her diagnosis.

Despite her own ability to find a match, it does not surprise me that Gina's concern is on a larger scale, recognizing the fact that many others are not as fortunate as herself. While the chances of finding a complete match among Caucasians has risen from approximately 30% to nearly 80% over the past 25 years with the expansion of the NMDP registry, the chances of finding a match for patients with other ethnicities is significantly lower, ranging from 30-50% for African American, Asian, and Latino populations. Novel approaches to this problem such as the use of cord blood transplantation is still in its infancy and carries a significantly higher risk compared with matched unrelated bone marrow transplantation.

We urge you to consider Gina's story in evaluating the proposed bill. If a donor had not been available for her, it is possible that her voice would not be heard today. In addition, thousands of her students would not have the opportunity to meet and learn from such a remarkable individual. She is truly an inspiration and an example of how this bill may affect future generations.

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